UNITED STATES DISTRICT COURT FOR THE EASTERN DISTRICT OF MICHIGAN

EZRA ZABAWA,

Honorable

Plaintiff,

Case No:

٧.

MICHIGAN DEPARTMENT OF HEALTH AND HUMAN SERVICES; and NICK LYON, Director of Michigan Department of Health and Human Services in his official capacity,

Defendants.

MICHIGAN PROTECTION & ADVOCACY SERVICE, INC.

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COMPLAINT FOR INJUNCTIVE AND DECLARATORY RELIEF

Plaintiff, Ezra Zabawa, brings this action to redress Defendants' violations of Plaintiff's right to medically necessary private duty nursing services. In support of this Complaint, Plaintiff alleges as follows:

I. JURISDICTION AND VENUE

- 1. Plaintiff asserts civil claims pursuant to Title II of the Americans with Disabilities Act ("ADA"), 42 U.S.C. § 12132 *et seq.*; Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794; and the Social Security Act, 42 U.S.C. § 1396 *et seq.* ("Medicaid Act").
- In addition, Plaintiff asserts a civil claim authorized by 42 U.S.C. § 1983 to redress the deprivation of Plaintiff's rights guaranteed by the Medicaid Act.
- 3. This Court has federal question jurisdiction over Plaintiff's claims pursuant 28 U.S.C. §§ 1331 and 1343.
- 4. Plaintiff's claims are properly brought in this venue and district pursuant to 28 U.S.C. § 1391(b), because the acts and omissions giving rise to the claims occurred in Oakland County or Monroe County, Michigan.

II. PARTIES

- 5. Plaintiff, Ezra Zabawa, age 19, has been diagnosed with congenital muscular dystrophy and nocturnal hypoventilation. Ezra is eligible for Medicaid-funded services, including the services authorized by the Early Periodic Screening, Diagnostic, and Treatment ("EPSDT") provisions of the Medicaid Act, 42 U.S.C. § 1396d(r)(5).
- 6. Ezra is a qualified individual with a disability within the meaning of the ADA and the Rehabilitation Act.
- 7. Ezra has substantial functional limitations in self-care, mobility, and the capacity for independent living within the meaning of MCL § 330.1100a(25).
- 8. Ezra is capable of living in the community with support services. He has chosen to live in his family's home, with Medicaid support services.
- 9. Defendant, Michigan Department of Health and Human Services ("MDHHS"), is the single state agency responsible for administering and implementing Michigan's Medicaid program.
- 10. Defendant, Nick Lyon, is the Director of MDHHS.

- 11. As Director, Nick Lyon is responsible for ensuring that Michigan's Medicaid program is administered and implemented in accordance with the requirements of federal law.
- 12. At all times relevant to this action, Defendant Lyon has acted under color of state law.

III. Applicable Statutory Provisions

A. The EPSDT Medicaid Program in Michigan

- 13. Plaintiff incorporates by reference paragraphs 1 through 12 as if fully set forth herein.
- 14. The Medicaid program is jointly funded by the state and federal governments in accordance with Title XIX of the Social Security Act.
- 15. Michigan must operate and administer its Medicaid program in compliance with federal Medicaid statutes and regulations.
- Under federal law, Defendants are mandated to provide EPSDT services to Ezra without any delay caused by Defendants' procedures.
 42 C.F.R. § 435.930(a).
- 17. The EPSDT provisions require Defendants to provide Ezra with services that are medically necessary to correct or ameliorate Ezra's health conditions. The required services include private duty nursing to maintain Ezra's current health.

B. The Americans with Disabilities Act (ADA)

- 18. Title II of the ADA provides that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." 42 U.S.C. § 12132.
- 19. Title II's implementing regulations require that "[a] public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d).
- 20. Segregation from the community, and unjustified institutionalization both constitute discrimination prohibited by Title II.

C. Section 504 of the Rehabilitation Act

- 21. Section 504 of the Rehabilitation Act prohibits discrimination against individuals with disabilities under any program or activity receiving federal financial assistance. 29 U.S.C. § 794(a).
- 22. Defendant, MDHHS, receives federal financial assistance for the Medicaid EPSDT program.

- 23. The Rehabilitation Act's implementing regulations require Defendants to "administer programs and activities in the most integrated setting appropriate " 28 C.F.R. § 41.51(d).
- 24. The implementing regulations prohibit Defendants from directly, or through other arrangements, utilizing criteria or methods of administration that effectively subject individuals with disabilities to discrimination on the basis of their disabilities. 28 C.F.R. § 41.51(b)(1)(vii)(3).

IV. Facts

- 25. Plaintiff incorporates by reference paragraphs 1 through 24 as if fully set forth herein.
- 26. Muscular dystrophy is causing progressive weakening of Ezra's muscles. He cannot walk. He can move his arms and hands minimally. He needs assistance with all activities of daily living.
- 27. Specifically, muscular dystrophy has attacked the muscles that Ezra uses to swallow and to breath. Accordingly, Ezra must use a gastronomy tube for daily nutrition. In addition, to be able to breathe at night, Ezra must use a pressure ventilator with a face mask. Ezra also uses the ventilator during the day when needed to maintain his pulmonary health.

- 28. If Ezra aspirates fluid into his lungs, he is unable to clear the fluid, and he could suffocate and die. The ventilator face mask increases this aspiration risk.
- 29. Ezra requires skilled nursing care to assess his pulmonary function, evaluate him for any aspiration, implement emergency plans, and maintain his pulmonary health. During every shift, skilled nursing staff must determine what interventions are necessary, and must perform those interventions to maintain Ezra's health.
- 30. As of November 28, 2016, Ezra's treating physician had authorized up to 372 monthly hours of private duty nursing for Ezra. For a 31-day month, this authorization amounted to an average of 12 hours of private duty nursing each day.
- 31. As of November 28, 2016, Ezra's treating physician ordered that skilled nursing staff must maintain Ezra's oxygen saturation level at 93% or higher. The physician ordered that he is to be notified whenever Ezra's oxygen saturation level drops for more than 20 minutes.
- 32. The treating physician's order requires that the skilled nurses keep an emergency ventilator within their reach for Ezra at all times.
- 33. Because Ezra has very limited mobility, he is at risk of skin breakdowns. He requires skilled nursing care to evaluate and treat him

- for all skin breakdowns. He also requires skilled nursing care to manage and assess his gastronomy tube feedings.
- 34. As of November 28, 2016, the treating physician categorized Ezra's prognosis as "fair."
- 35. On January 9, 2017, Ezra's treating physician confirmed the same orders he had previously issued, including 372 monthly hours of private duty nursing, tube feedings, treatment for skin breakdowns maintenance of oxygen saturation levels, and notification of the physician anytime Ezra's oxygen saturation dropped for more than 20 minutes.
- 36. On January 9, 2017, Ezra's treating physician again categorized Ezra's prognosis as "fair."
- 37. For at least the past five years, Defendant, MDHHS, had authorized 12 hours of private duty nursing per day for Ezra, through the Michigan Medicaid program. The authorization provided one nurse for 12 hours daily, who provided services to Ezra and to Ezra's older brother, who also has muscular dystrophy.
- 38. From November 28, 2016 through the date of filing of this Complaint, there has been no improvement in Ezra's medical condition. Given the

- progressive nature of muscular dystrophy, no improvement in Ezra's condition is anticipated.
- 39. On February 21, 2017, Defendant, MDHHS, notified Ezra and his brother that as of May 1, 2017, their private duty nursing services would end.
- 40. According to the notification issued by Defendant MDHHS, Defendant terminated Ezra's private duty nursing services on the ground that Ezra "does not meet PDN [private duty nursing] criteria, has had no hospitalizations, uses BIPAP [ventilator] only at night, and has sixty (60) hours of CLS [community living support] services per week."
- 41. The notification issued by Defendant MDHHS referenced three sections of the MDHHS Medicaid Provider Manual section regarding Private Duty Nursing: Sections 1.7, 2.3, and 2.6. These sections categorize private duty nursing services as a "transitional benefit."
- 42. Ezra and his brother each filed administrative appeals to retain their previously authorized private duty nursing services. During the pendency of the administrative appeals, Defendant MDHHS provided Ezra with private duty nursing services.

- 43. During the pendency of the administrative appeals, Ezra's brother turned age 21. Ezra's brother is now seeking private duty nursing services through a separate program.
- 44. On August 14, 2017, Ezra received notice that his administrative appeal had been denied.
- 45. Defendant MDHHS has notified Ezra that as of midnight on August 31,2017, he will receive no further private duty nursing services.

V. LEGAL CLAIMS

Count I: 42 U.S.C. §1983 action for violation of Ezra's EPSDT rights

- 46. Plaintiff incorporates by reference paragraphs 1 through 45 as if fully set forth herein.
- 47. Ezra's right to receive private duty nursing is secured by the laws of the United States, including, but not limited to, the Medicaid Act, 42 U.S.C. § 1396 *et seg*.
- 48. Defendants' application of the Michigan private duty nursing criteria has deprived Ezra of his right to private duty nursing services.
- 49. Defendants' classification of private duty nursing as a "transitional benefit" is directly contrary to the provisions of the EPSDT.

- 50. Defendants' failure to continue Ezra's private duty nursing services violates the EPSDT mandate, which requires that Defendants provide Ezra with all medically necessary services to ameliorate his condition.
- 51. There has been no change in Ezra's condition to warrant termination of private duty nursing services.
- 52. Ezra has not been weaned from his use of a ventilator, and there is no expectation that Ezra will be weaned from the use of a ventilator.
- 53. There has been no change in Ezra's living situation to warrant termination of private duty nursing services.
- 54. Any cessation or delay in the provision of private duty nursing services may result in Ezra having an acute episode of aspiration, which could cause him to suffocate and die.
- 55. Defendants have failed to continue the private duty nursing services that are essential to maintain Ezra's health.
- 56. Defendants' failure to continue the private duty nursing services places Ezra at serious risk of harm, including the risk of hospitalization and death.

Count II: Violation of Title II of the Americans with Disabilities Act (ADA)

- 57. Plaintiff incorporates by reference paragraphs 1 through 56 as if fully set forth herein.
- 58. Defendant MDHHS is a public entity within the meaning of Title II of the ADA.
- 59. Defendant Lyon, acting in his official capacity, is a public entity or official within the meaning of Title II of the ADA.
- 60. Defendants' failure to continue private duty nursing services has placed Ezra at imminent risk of harm, and at serious risk of institutionalization.
- 61. By failing to continue private duty nursing services, Defendants have violated and are violating Title II of the ADA by failing to provide meaningful alternatives to institutionalization.
- 62. Providing Ezra with timely access to private duty nursing services would not fundamentally alter the Defendants' service system.
- 63. Defendants' decision to terminate Ezra's private duty nursing services constitutes discrimination within the meaning of Title II of the ADA.
- 64. As a direct and proximate result of Defendants' discrimination, Ezra is at serious risk of institutionalization.

65. Absent injunctive relief to require Defendants to continue Ezra's private duty nursing services, Ezra will sustain injuries and damages.

Count III: Violation of Section 504 of the Rehabilitation Act of 1973.

- 66. Plaintiff incorporates by reference paragraphs 1 through 65 as if fully set forth herein.
- 67. Ezra is qualified to participate in Medicaid with or without reasonable modifications to Defendants' rules, policies, or practices.
- 68. Defendants have violated and are violating Section 504 of the Rehabilitation Act of 1973 and its implementing regulations by using methods of administration that substantially impede the mandates of the Medicaid program.
- 69. This violation includes, but is not limited to, Defendants' failure to continue medically necessary Medicaid services for Ezra.
- 70. Defendants' administration and management of the Medicaid program places Ezra at serious risk of institutionalization.
- 71. Defendants have violated and are violating Section 504 of the Rehabilitation Act of 1973 and its implementing regulations by administering, funding, and operating their service system in a manner that fails to make services available in a timely manner and able in the most integrated setting appropriate to Ezra's needs.

- 72. Providing Ezra with timely access to private duty nursing services will not fundamentally alter the Defendants' service system, because the federal laws already mandate that private duty nursing services be provided.
- 73. As a direct and proximate result of Defendants' discrimination, Ezra is at serious risk of institutionalization.
- 74. Absent injunctive relief to require Defendants to continue Ezra's private duty nursing services, Ezra will sustain injuries and damages.

Count IV: Violation of the Social Security Act Title XIX's EPSDT provisions.

- 75. Plaintiff incorporates by reference paragraphs 1 through 74 as if fully set forth herein.
- 76. Ezra is a Medicaid beneficiary authorized to Medicaid-funded services that his treating physician has determined to be medically necessary to correct or ameliorate Ezra's condition.
- 77. Ezra is entitled to these medically necessary services under 42 U.S.C. §1396d(r).
- 78. Defendants have failed to provide medically necessary EPSDT services in violation of 42 U.S.C. § 1396 et seq.

79. Absent injunctive relief to remedy Defendants' violation of the EPSDT provisions, Ezra will suffer irreparable injury.

REQUESTED RELIEF

Wherefore, Plaintiff respectfully requests this Court to:

- A. Declare Defendants violated and are violating Ezra's rights under Section 504 of the Rehabilitation Act and Title II of the ADA.
- B. Declare that Defendants have violated and are violating Ezra's rights under the Medicaid Act's EPSDT provisions.
- C. Order Defendants to authorize private duty nursing services for Ezra, and impose penalties upon Defendants for any failure to comply with that order.
- D. Enter a judgment against Defendants in an amount consistent with damages sustained.
- E. Grant attorney's fees and costs.
- F. Grant all other necessary and appropriate relief.

Respectfully submitted,

Dated: August 31, 2017 By: /s/ Sherry McGrath

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